

109 Research Involving Foster Children In Child And Family Services Custody

Major objectives:

Child and Family Services will cooperate with bona fide research by providing information on foster children in the custody of Child and Family Services as long as the research is approved in accordance with the standards and procedures of the Department of Human Services Institutional Review Board, which may be found on their Website at <http://www.hs.utah.gov/irb/index.htm>.

Applicable Law

FDA 21 CFR 50, FDA 21 CFR 56; DHHS 45 CFR 46.

Utah Code Ann. [§52-4-1 through 7](#). Open and Public Meetings.

Utah Code Ann. [§53A-13-301](#). Application of State and Federal Law to the Administration and Operation of Public Schools.

Utah Code Ann. [§63-2-101 through 909](#). GRAMA.

Utah Code Ann. [§62A-3-302](#). Purpose of Adult Protective Services Program.

Utah Code Ann. [§62A-4a-403](#). Reporting Requirements.

Procedures

A. When a researcher proposes a research study that involves children in Child and Family Services custody, the following steps must be taken to grant informed consent prior to the researcher being given any confidential information. Federal regulations define "research" as "*a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge.*" This may include, but is not limited to, accessing individual client records, interviewing the child or others about the child, observing the child, or treating a child as part of the research study.

1. The Child and Family Services research representative to the Department of Human Services Institutional Review Board (DHS IRB) and the Child and Family Services Division Director must review and approve the research. The review will consist of evaluating whether or not the research is in the best interests of Child and Family Services and its clients (including the children), the researcher has made adequate provision for obtaining all required informed consents and informed assents, the research protocols and procedures are designed to ensure confidentiality, respect, and ethical treatment during the researcher's gathering of the data, storage, retrieval of the data, and publication of the data, the

- research study involves no more than minimal risk to subjects or the direct benefits to the subjects outweigh the risks, the research methodology is sufficiently sound to yield results that offer a potential benefit to the Department or Child and Family Services, and the research protocol protects individual privacy rights and complies with the Department's Vision and Mission Statements, the Department Code of Ethics, and any applicable rules or statutes, including Utah Code Annotated [§63-2-202\(8\)](#). Approval will be documented on the Division Level Approval of Research Form (see Section 109 Appendix, Foster Children Research Involvement - Caseworker Consent Form).
2. The DHS IRB must review and approve the research in accordance with Department of Human Services policy "Protecting the Rights of Human Research Subjects Policy and Procedures", FDA 21 CFR 50, FDA 21 CFR 56; DHHS 45 CFR 46; Utah Code Annotated [§52-4-1 through 7](#) Open and Public Meetings; Utah Code Annotated [§53A-13-301](#) Application of State and Federal Law to the Administration and Operation of Public Schools; Utah Code Annotated [§63-2-101 through 909](#) GRAMA; Utah Code Annotated [§62A-3-302](#) Purpose of Adult Protective Services Program; Utah Code Annotated [§62A-4a-403](#) Reporting Requirements.
 3. Informed consent for children in Child and Family Services custody (unless written consent has been waived by the DHS IRB):
 - a. The Child and Family Services caseworker for the child will consult with the foster parents (adoptive parents in research with adoptive children) and may contact therapists, school personnel, and others who work closely with the child to determine if the child will be available and ready to participate in the proposed research, and to consider if there are any concerns about the child participating in the research. If it is decided that the child can participate, the caseworker must sign the informed consent and document who they consulted prior to deciding to give consent.
 - b. If the child is under 18 years of age and the goal of the child is 'Return Home' or 'Custody to Relative Guardian' or if parental rights have not been terminated, the parents or relatives must be consulted and give their permission for the child to participate. If they give their permission they must also sign the informed consent form. If they do not give their consent the child cannot participate in the research.

- 77 c. If the child has the maturity to understand the implications of
78 participating in research, they must be consulted about their
79 potential participation. It must be explained that participation is
80 voluntary, if they do not assent it will not in any way affect services
81 they or their families receive from Child and Family Services, and if
82 they do assent they can withdraw from the research project at any
83 time without penalty. Evaluation of the child's level of maturity is
84 done by the Child and Family Services caseworker after
85 consultation with foster or adoptive parents and other appropriate
86 collateral contacts (i.e. education representatives, a therapist,
87 caretaker, etc.). If the child agrees to participate, he or she must
88 sign an informed assent form. If the child is 18 years or older they
89 must sign the informed consent form. If the child does not agree
90 they cannot participate in the research.
- 91 d. The office of the Guardian ad Litem (GAL) must be contacted. The
92 GAL representing the child must be given a description of the
93 research project. If the GAL expresses concerns regarding the
94 child's participation in the research, the child cannot participate.
95 The GAL may be contacted via phone or certified mail. They need
96 to be provided the anticipated start date for the research. They also
97 need to be provided a date by which response is required so that
98 they can express any concerns they have prior to then. The GAL
99 must be given at least 10 days to review and respond to the
100 research proposal. Contact with the GAL must be documented for
101 each child.
- 102 e. Consent forms, assent forms, and documented contacts will then be
103 sent to the Child and Family Services research representative to be
104 stored with the research proposal.
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- 106 B. Once these steps have been completed and if proper consent and assent have
107 been given, the Child and Family Services research representative may release
108 information to the researcher.
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